

Arizona Department of Health Services
Office for Children with Special Health Care Needs

Community Development Initiative and Recommendations for Extending Collaboration

Goal

The goal of the Office for Children with Special Health Care Needs is to develop self-reliant, self-sustaining community organizations that mobilize local, state and federal resources to improve the quality of life for children with special health care needs and their families.

Rationale

Organized communities, acting in partnership with state agencies produce more relevant assistance and support to benefit all of their members than can passive, isolated clients acting as recipients of services. Development starts with the belief in strength and capacities; its approach seeks to build capacities of all people so that they are more fully able, not more fully served. Communities themselves are changed intentionally – their strengths are recognized and developed so that conditions that affect people improve – while extending the availability and efficiency of resources. Community development seeks to change conditions that affect people rather than changing people who are affected by conditions.

Outcomes

The resulting outcomes include the:

- development of experienced and competent parent leadership, evidenced by both a community and statewide presence of parent leaders who demonstrate passion, energy and commitment to the work;
- formation of parent/professional partnerships which facilitate meaningful parent involvement and increase mutual understanding and action;
- formation of statewide, linked, action-oriented community organizations that address community issues and discover, connect, create and mobilize community resources;
- concern, vision and energy of parents dedicated to improving their communities, not only for their children with special needs but for all children and families;
- increased understanding on the part of professionals in knowing how to help families as well as families knowing how to seek help;
- improvement of community service delivery through coordination and partnerships;
- development and implementation of policies supportive of children and families, and
- promotion of child, youth and family access to full participation in the life of a community that nurtures and values all of its members.

Requirements

Four elements are required to engage in this community development work:

- Cause
- People
- Resources
- Process

1. Cause

There must exist a compelling cause or purpose to promote the emergence of a source of committed leaders and to motivate people coming together to accomplish a specific vision and mission. It is most typically those who are impacted by an issue or those who work to address it. As needs are addressed and abilities expanded, community resources, capacities and quality of life are enhanced for all children and families.

2. People

The work includes dedicated people or “champions” with both family members and professionals represented. There must be access to expertise in community development theory and practices and an ability of champions to engage in meaningful relationships, as well as to play a supportive, encouraging role in developing new leadership and promoting the learning of others.

3. Resources

Resources include funding as well as other assets, such as time, expertise, materials, etc. Minimal, but flexible, funding must be available to support continuous convening of people, to reimburse parent leaders for their expertise, time and expenses and to provide sufficient financial backing that gives the work legitimacy. Seed money facilitates the ability to obtain money from other community and external sources of support. Utilizing and mobilizing other tangible assets increase the range and depth of community investment and expands opportunities. Individual and community capacities are increased as all people learn to develop their own resources.

4. Process

A purposeful, consistent process guides the development of leadership and community team formation. It includes a patient, long-term commitment of community development work and learning “on the job”, ongoing and frequent mechanisms that facilitate communication, reflective practice and learning. Leadership and community development techniques and strategies promote the involvement of both individuals and groups. Being invited into communities, conducting community assessments that identify resources as well as issues, taking action and measuring success are key steps in the development process. ***See attached Protocol for Community Development*** for specific steps in the community development process.

Accomplishments and Opportunities

The Office for Children with Special Health Care Needs (OCSHCN) Community Development Team and Parent Leaders have learned much over that last 10 years in accomplishing their goals. Eleven parent-led community action teams (representing 23 communities) include participation from families and representatives from medical, education, social services, public health and community sectors. Positive, genuine collaboration and coordination is emphasized, in addition to building on community assets, community ownership of direction and increasing skills of individuals. Members of the statewide community organizations are also linked through monthly Parent Leader communication, a shared website and newsletter, a biennial conference and staff visits and updates. All participants engage in a supportive, exciting learning atmosphere of discovery.

Currently, there are thirty (30) skilled Parent Leaders who play increasingly significant roles in setting policy and directing resources within communities and state entities.

Supported financially by ADHS/OCSHCN, they participate in a purposeful program of ongoing technical assistance, training, support, communications, planning and evaluation. Parent Leaders have built strong, cohesive organizations. They have improved service delivery for children with special needs within their communities by expanding providers, coordinating existing programs and obtaining new resources. And, they have increased citizen skills, awareness and interaction with children, youth and adults with special needs and their families by connecting people, building relationships and providing educational opportunities. Their efforts and this approach have attracted two significant federal grants to Arizona that incorporate the community organization infrastructure as a key element to their objectives.

Because this initiative has been successful, interest in this work continues to grow with new parents and other communities, agencies and levels of government. Parents confirm the value of the work and are inviting others to build upon what has already been achieved. Professionals are considering ways to further enhance the work while ensuring that efforts will not be duplicated. The opportunities are plentiful and timely.

Recommendations

Recommendations for the further enhancement of this work include four aspects:

1. Promoting and expanding parent leadership and parent involvement as well as the participation of communities in setting policy and directing resources;
2. Facilitating purposeful support from other agencies, in conjunction with existing community action teams;
3. Partner with other agencies to develop steps they might take in regions or communities in which there are no active (OCSHCN) community action teams; and
4. Develop effective mechanisms for coordination of efforts.

These four aspects are addressed in the following recommendations:

Actions taken by State and Local Agencies to Implement a Developmental Approach

- State agencies commit to seek out parent and community collaboration in the setting of policy and resource allocation. Policymakers visit, communicate and collaborate with Parent Leaders, team members and other community leaders. This action will lead to a greater understanding and definition of parent and community roles and support.
- State agencies adopt a collaborative development approach that allows issues to surface and connect with worthy actions.
- State and local agencies ensure family-centered practices and standards in service delivery through various strategies, including engaging parents to provide training to professionals.
- State and local agencies identify and support specific “champion” staff whose job is to become informed and participate in community development work. This may include active, meaningful participation in existing community action team activities, which provides exposure to and confidence in this way of doing business or working to initiate teams in communities not currently represented. Designated funding provides staff opportunities to attend educational events or engage experts in parent leadership and involvement and community development, such as current

Parent Leaders. Efforts are taken to build upon what currently exists and respect initiatives underway.

Actions taken to Facilitate Expansion of Parent Leaders and Parent Involvement

- State and local agencies identify potential parents (of clientele served) who would like to become parent leaders in areas not currently represented such as Behavioral Health, Juvenile Probation, Child Protective Services, Department of Education and School Districts, AHCCCS, ALTCS, Hospitals, Physicians and Teaching Institutions (colleges and universities). OCSHCN offers to include new Parent Leaders and other agency staff in their Community Development Technical Assistance process.
- A process of financial reimbursement for parent time and expertise is developed by all agencies. Parent Leaders are reimbursed for their time and expenses when engaged in agency specific tasks and for participation on community action teams, representing specific agencies. New Parent Leaders have access to training and technical assistance.
- A policy that ensure agencies make policy decision impacting children with special needs with the meaningful participation of parents.
- A parent led gathering of state leaders, staff and community families, leaders and professionals are organized to coordinate the efforts of all agencies engaged in parent leadership and community development work. The group itself develops Memorandums of Agreement to blend efforts and resources. Participants would fashion the vision, mission and activities of the group.

Actions taken by State Agencies and Community Partnerships to Ensure Collaboration

- Organize and conduct community directed campaign that challenge communities to recognize their abilities and responsibilities to all children and families, including children with special needs.
- Agencies develop ways of supporting and partnering with community team initiatives through designated or in-kind contributions as well as modifications to policies, as needed. Partnering includes attendance at meetings and the availability to share in the work.
- Agencies adopt a development approach, which produces a multiplier effect upon current resources, allowing creation of community resources to complement and accelerate agency and other resources.
- In communities where no action teams exists, OCSHCN Parent Leaders and staff offer to collaborate and provide technical assistance, training and materials to agencies interested in initiating a parent and professional community team, ensuring coordination and avoiding duplication of efforts. Specific action steps are provided from initial group formation to action mobilization.

Conclusion

The creative and committed energy of parent leaders and communities have been unleashed. Inviting and supporting the participation of new youth with special health care needs, new parents and caregivers of children with needs, new communities and additional agencies is timely. Combined dedication and hard work that is currently underway, by many individuals and agencies, Arizona's road to accomplishment will continue to evolve.